DOCUMENT RESUME

ED 342 556 RC 018 508

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TITLE Disability Rights and Independent Living Movements.
PUB DATE 18 Mar 91
NOTE 9p.; In: Reaching Our Potential: Rural Education in the 90's. Conference Proceedings, Rural Education Symposium (Nashville, TN, March 17-20, 1991); see RC 018 473.
PUB TYPE Speeches/Conference Papers (150) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Activism; Advocacy; *Disabilities; Employment Opportunities; *Independent Living; *Leadership; *Rural Areas; Social Action; *Special Education Teachers
IDENTIFIERS Americans with Disabilities Act 1990; *Center for Independent Living

ABSTRACT

This paper describes the Disability Rights and Independent Living movements, and advocates for increased awareness and leadership. The Independent Living Movement started at the University of California in the 1960s when a group of severely disabled students organized a place where they could live independently. Despite their education and competence, these disabled people could not find employment in their fields. With financial assistance from Rehabilitation Services, they started the first Center for Independent Living, where they planned to give disabled people a chance to gain work experiences and become more competitive in the job market. The goals of the Independent Living and Disability Rights Movements include: (1) integration into all aspects of society; (2) equal opportunities; (3) freedom of choice regarding where to live and where to work; and (4) self-determination and control over one's life and affairs. The Independent Living (IL) Movement emphasizes advocacy and social activism, but IL programs have overlooked rural areas. Many disabled students in rural areas face limited options and are often forced to enter nursing homes. Leadership and IL programs are needed in rural areas. Information about the Independent Living and Disability Rights movements can be incorporated into the curriculum so that special education students can learn to become self-advocates and develop their potential leadership abilities. (KS)

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ED342556

NRSSC PRESENTATION
Presenter: Karen Hirsch
Co-Presenter:
Day: March 18, 1991
Time: 1:30pm - 2:30pm

Disability Rights and Independent Living Movements

RC018508

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Disability Rights and Independent Living Movements

The major purpose of this paper is to tell the story about Disability Rights and Independent Living (IL), two interconnected movements that are gaining strength within the community of disabled people in the United States and to bring this story to special education teachers who work in rural areas. In so doing I hope to affect some of the disabled individuals who live so far away from established Centers for Independent Living that they may not have heard about, much less become part of, the changing attitudes and the growing sense of community that is on the rise among disabled people in the world today.

Special education teachers are already involved in transition programs, as when they work with Rehabilitation Services and other agencies to help students with disabilities leave the school and successfully enter the work force or find a role for themselves as they begin the adult phase of their lives. IL programs--run by disabled people and serving disabled people--represents another resource for this process, and because of their unique qualities these programs play a vital role for some disabled adults in the areas of the country where they are located. Special education students in rural areas need a chance to join the Independent Living and Disability Rights movements, and special education teachers have a chance to bring them this information.

The American with Disabilities Act (ADA) of 1990, P.L. 101-336, became law in part because of intense lobbying by a nationwide network of disabled activists. Many of these activists first became involved in the Disability Rights movement through their contact with a local Center for Independent Living. A large army of disabled people joined letter-writing campaigns and telegram blitzes in support of the ADA at different crucial times during its passage through the Senate, the House, and various congressional committees during 1989 and 1990. Many of these disabled activsts were spurred into action by information about the bill and specific instructions for what to do that were distributed by local IL centers as well as national advocacy organizations.

The Independent Living Movement was born in Berkley, California in the 1960s when a group of severely disabled students at the University of California decided to move out of the infirmary, or student health center, and organize a place where they could live independently away from the supervision of medical personnel. They succeeded in setting up an accessible place to live, arranging for and managing their own attendant services, and achieving independence and self-determination while completing their education.

What they still had trouble with was finding jobs. In spite of formal qualifications and high levels of competence, these

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severely physically disabled people with college degrees could not find employment in their fields. With financial assistance from Rehabilitation Services, they started their own program, the first Center for Independent Living, where they planned to give disabled people a chance to gain work experiences and become more competitive on the job market. Finding employment outside centers for IL has remained difficult for most severly disabled job seekers. But as IL centers similar to the first one in Berkley have been set up across the United States, a different outcome has emerged: a new model for providing services for people with disabilities.

Independent Living as a service delivery model has been described by Gerben DeJong (1978, 1983). His direct comparisons between the Independent Living and Rehabilitation Services programs are especially interesting. While the Rehabilitation Services model puts the locus of the problem in the individual, the disabled person who needs to be "rehabilitated" so that he or she can become ready for the competitive job market, the Independent Living model puts the locus of the problem on the inaccessible environment, emphasizing the need to remove existing barriers in the community so that people with disabilities can have equal opportunities with non-disabled people in their search for employment. The locus of control over the program and the delivery of services also differs between the two models. In Rehabilitation Services the locus of control lies with the professional counselor, whereas in Independent Living the locus of control is clearly vested in the disabled person, the consumer of the services.

For teachers as well as rehabilitation counselors, it has not been easy to begin to see that the delivery of services could be effective if controlled by the "recipients," the clients. Giving the clients a more active role, the role of "consumer," a role that already has a familiar ring in the mind of the American public, has proven to be empowering for disabled people and has given them an opportunity to practice independence and self determination. It is one of the key elements of the IL model that make these programs effective.

Some of the ideas that have emerged from the IL movement have been somewhat altered as they have been integrated into special educational and rehabilitation literature. The phrase "independent living" is now being used to mean a wide variety of things, especially notable are segregated apartments or houses that are organized by professionals so people with disabilities can live there. This meaning of "independent living," however, does not conform with the original philosophy of the Berkley group, nor with the spirit of the large network of programs and individuals that make up the "Independent Living Movement." Integration into all aspects of society: equal opportunities; freedom of choice for where to live and where to work and what to participate in; self-determination and control over one's own life and affairs; these are the goals of both the Independent Living and Disability Rights Movements.

One of the most important aspects of the Independent Living movement is the emphasis on advocacy and social activism. The list of services that a typical IL program provides includes both

advocacy on behalf of disabled individuals and systems advocacy--efforts to change a community's policies and general level of accessibility. Independent Living programs are mandated to be administered and managed by disabled people, and to include individuals from all different types of disability groups. Until now, most IL centers have been established in large metropolitan centers, and the typical IL program model is better suited for providing services in urban settings. As a result, less advocacy for accessibility has been done in rural areas, and less information about programs, legislation, and networking has reached individual disabled citizen in these areas. In short, public places are less accessible for disabled people in the country side, and successful integration in community life remains even more difficult for disabled citizens in rural than in urban areas.

Since the passage of Public Law 94-142 in 1975 there has been an increasing number of students with disabilities who have been receiving a "free and appropriate" education in the "least restrictive environment" and who have been graduating or leaving school with the expectation of continuing their life in the local communities along with their non-disabled peers. The trouble is that society is less accessible and less ready for integration than schools. In spite of the stated goal of the Office of Special Education Programs "to facilitate the movement of each student with a handicap from a school/home environment to the fullest possible participation in the society at large" (U. S. Department of Education, 1990, p. 108), the National Council on Disability provides a pretty dismal picture of what reality is like for students with disabilities. While 56% of all students attended post-secondary education programs in the mid eighties, the comparable number for students with disabilities was 15%, and while the national unemployment rate was 5%, the unemployment rate among people with disabilities was 14.2% (National Council on Disability, 1989).

For many disabled students, especially those living in rural areas, the end of school attendance far too often means the end of services and the end of meaningful activities. Many disabled young adults face a restrictive set of options: they could move to a city where they might find services and accessible activities, if not employment, or they might end up staying at home with their parents as long as the parents are able to help with the attendant services they need, or, all too often, they are forced to enter geriatric nursing homes because that is their only option.

People who do not have first hand experiences that confirm such situations find it hard to believe that a nursing home can be the only choice a bright, young disabled person could have. As a director of an IL center in the South covering both an urban and a large rural area, I had to develop an order of selection for who would have first, second and subsequent priorities for receiving the limited services available. Like many other IL centers, our top priority was to keep young disabled adults from ending up in a nursing home.

Equal opportunities and community integration for severely disabled people in housing, employment, education, recreation,

and civic activities, requires that an array of coordinated services are available simultaneously. Accessible transportation, affordable and accessible housing, accessible communication systems, attendant services, reasonable assistive technology, and accessible public and educational facilities are all needed for a disabled person to be able to function independently as an integrated member of the community. One of the reasons why communities, especially rural communities, are lagging so far behind in providing the kinds of services that are needed, is that too much of the resources being spent on programs for people with disabilities are still being spent on large institutions rather than community based programs. For example, until recently, of all federal reimbursements to states for the care of mentally retarded and developmentally delayed persons, 75% of the money went to large institutions where 3% of the mentally retarded people were living (Ferguson, Hibbard, Leinen, and Schaff, 1990). Programs for people with mental illness are even more biased toward institutions, since in that field there has not yet developed a network of community based services that addresses the need of these people for integrated housing and employment.

Effective centers for Independent Living provide community education about disability issues. The local press is often invited to a community IL center to get a story from a Disability Rights perspective. But it is not easy for disability activists to get their story reported, and if it is included, the tone of it is often changed from a Disability Rights issue to a story that is celebrating a disabled hero or calling attention to the inspirational courage of person who is overcoming severe obstacles and "not letting a disability get him down." The inability of the press to see disabled people as an integral part of a community's cultural and political life, is an accurate reflection of the relationship between communities and most of their disabled citizens. As long as the physical and attitudinal barriers are allowed to exist, a disabled person cannot participate in community activities as if they are ordinary events in that person's life. The disabled person feels excluded by the community, and the community ignores and forgets about its disabled citizens.

Children with disabilities who are still in school do not have many role models of competent and mature disabled adults who are trusted members of the community and who are going about their lives in an ordinary way. Special education programs often harm rather than help disabled children's social integration and acceptance by their non-disabled peers. Feelings of loneliness and insecurity paired with delayed social development are too often secondary characteristics of disabled kids. Independent Living programs with their emphasis on peer counseling offer at least the opportunity for an alternative peer group and a chance to find adult role models.

Since most of the IL centers that have been established so far are located in or near urban centers, it is the urban cultural settings that mostly have shaped the thinking of the leaders in the Independent Living Movement. Some of the advocacy agendas of these programs are unacceptable and even disturbing to

disabled people with leadership potentials whose sense of cultural connections have rural rather than urban roots. These two groups of people have not yet started a dialogue or even discovered that they need to communicate. Somehow the rural, or non-urban, points of view need to become better articulated for what they can contribute to the development of the Independent Living and Disability Rights movements. One way of promoting this would be to attempt to set up Independent Living centers in rural areas and to let the local needs of the communities shape both the activities and the rhetoric of these centers, while still maintaining the basic elements of consumer control and advocacy.

A large number of existing centers for Independent Living are funded by Title VII, Part B, grants from the Department of Education channeled through the Rehabilitation Services Administration. Next year, 1991-92, it is quite possible that a large number of these grants will be opened up for renewed competition. It also would seem reasonable that areas which have not benefited from IL services before, might have an advantage in the application process. Programs that receive funding under this title must be governed and administered by disabled people. The governing body must be a non-profit agency that is based on consumer control, that is, at least 51% of the members of the board of directors must be people with disabilities. Information about the competitive call for proposals to start new IL centers should be brought to disabled people with leadership abilities who live in rural areas of this country and who have yet not joined this movement nor helped shape its message or stake out the direction of its course.

There is a severe crisis of leadership in the Independent Living Movement at this time. As the number of programs and individuals belonging to the IL movement has grown, so has diversity and the need for a clearly articulated set of common goals. The struggle to make sure that the American with Disabilities Act would become law has provided a clear rallying point for the disability community for some time, and now that it is over, disability activists must work even harder to identify the issues that will help the Movement go forward. The lack of clear mandates from its constituents is but one of the reasons that the IL movement is suffering from a shortage of strong leaders. Working in an IL program does not provide much in terms of job security since these centers are often funded by federal and/or foundation grants and other "soft" support from the local communities. A large number of disabled people have moved on from leadership positions in the IL movement to more secure and often highly visible positions within rehabilitation services programs, universities and other institutions that can offer greater stability and other employment benefits as well as opportunities to influence the development of disability policy within established agencies and government structures.

While a movement of disabled people into appropriate positions within other segments of society was one of the goals that the original Center for Independent Living was striving to accomplish, the current trend of constantly loosing its best leaders, makes it very difficult for the IL movement to keep its

momentum and politically sensitive focus. Some of the leaders among disabled people who may have first found their personal purpose and agenda through contacts with the IL movement, think that in general, centers for Independent Living have ended up placing too much emphasis on services for individuals while de-emphasize community advocacy. Thus, for some people IL was the place where they first started to think about disability issues and to develop the ideas that for them would come to constitute the broader and more important Disability Rights Movement.

The Independent Living and Disability Rights movements, while perhaps differing in scope over time, sprung from the same need for people with disabilities to speak up for their rights as citizens. Together these two movements make up the civil rights movement for Americans with disabilities. Ed Roberts, the "father" of Independent Living, who organized the first Center for Independent Living in Berkley, saw the Movement as "the wave of protest against segregation and discrimination and an affirmation of the right and ability of persons with disabilities to share fully in the responsibilities and joys of our society" (Roberts, 1977).

The Disability Rights Movement was born in the wake of, and benefited greatly from following the Civil Rights Movement, the Women's Movement, and a number of other social movements, such as the Consumer Movement. A number of similarities and differences can be seen when comparing these different movements. While the Civil Rights and the Women's movements had a relatively easy time defining the groups that they represented, the Disability Rights Movement has had an extremely difficult time coming up with an understanding of who the individuals would be that should be included in the defining group. The definition of who is and is not disabled, is in part a matter of personal choice and identity. A person with an invisible disability, for example, has the choice of identifying with being disabled or passing as non-disabled in most social situations. The similarities between these three civil rights movements are easily identified in areas like discrimination, segregation, lack of equal opportunities, and low status. Disabled people have learned to articulate their concern about these issues, in part, from the black Civil Rights and the Women's movements.

Being a member of a group that is denied its rights and is suffering from discrimination, does not automatically foster insights into the oppression, nor the ability to provide leadership to end it. Rather, the more effective the oppression, the less likely the group would be to develop a successful civil rights movement of its own. When considering most people with disabilities, the general perception is likely to be that they would need help from others--professionals or parents--in order to claim their rights. While this may always be the case for some disability groups, it may also be less true than first believed. Becoming your own best advocate can be and must be learned, from experiences and luck and inspirations, or from

Special education teachers in rural areas have daily contacts with young disabled people who are not likely to have heard about any of the issues discussed in this paper. If information about the Independent Living and Disability Rights

movements could be incorporated into the curriculum in such a way that special education students could learn about the issues, and learn to become self advocates, this might empower some of the students to take charge of their lives and develop their potential leadership abilities. Every disabled person with leadership potential is needed in the Independent Living and Disability Rights movements. Special education teachers could help develop these potential leaders. And every person, disabled or not, leader or not, who speaks out for full and equal access in the community, is helping to end discrimination and segregation of people with disabilities in the places where folks live, work, learn, travel, and play.

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